

Childhood autism diagnosis is getting better, but not for everyone

January 26 2023, by Dennis Thompson



Autism cases are surging in the New York-New Jersey metro area,

mainly fueled by the diagnosis of autistic children who don't have intellectual disabilities, a new study reports.

The percentage of kids identified with autism spectrum disorder rose from about 1% in 2000 to 3% in 2016 in that region, said lead researcher [Josephine Shenouda](#), program manager and epidemiologist with the Rutgers University Children's Research Center in New Jersey.

That increase occurred mainly due to new diagnoses of [autistic children](#) with a borderline, average or above-average IQ, according to findings published Jan. 26 in the journal *Pediatrics*.

"The driver of the increase of autism was really coming from identification of children with autism without intellectual disability," Shenouda said.

"Over that period, there was a twofold increase among children with autism with intellectual disabilities, but there was a fivefold increase for the children with autism without intellectual disability," Shenouda said.

The findings, along with recently revised federal statistics, refute the long-held notion that autism mainly occurs in intellectually disabled children, Shenouda said.

Only about one-third of autistic children have an IQ that is below average, according to both the new study and recent autism numbers released by the U.S. Centers for Disease Control and Prevention.

In the past, it had been estimated that up to 75% of autistic children had accompanying [intellectual disabilities](#), Shenouda said.

"What our paper shows is that this assumption is not true," Shenouda said.

Data from four New Jersey counties—Essex, Hudson, Ocean and Union—showed that about 32% of children diagnosed with autism had an intellectual disability, while about 59% had autism but no intellectual disability, results show.

Overall, documented cases of autism spectrum disorder increased threefold between 2000 and 2016, rising from 9.6 cases per 1,000 8-year-old kids to 31.8 cases per 1,000 kids, researchers said.

Rates of autism with intellectual disability doubled during that period, rising from 2.9 cases to 7.3 cases per 1,000 children, researchers said.

But cases of autism without intellectual disability jumped fivefold, from 3.8 to 18.9 per 1,000 children.

Both the New York/New Jersey metro area and the recent CDC report reflect an uptick in autism, said [Emily Hotez](#), a developmental psychologist and assistant professor with the University of California, Los Angeles David Geffen School of Medicine.

About 1 in 44 children were identified with [autism spectrum disorder](#) in the United States in 2018, the most recent year for which data is available, the CDC says.

That's up from 1 in 54 in 2016, and 1 in 88 in 2008, according to the CDC.

"These reports, from my perspective, are incredibly important for informing our understanding of autism, getting epidemiological estimates, as well as, probably most importantly, allocating necessary support and services and making that accessible and equitable," said Hotez, co-author of an editorial accompanying the Rutgers-led study in *Pediatrics*.

There are likely even more cases of autism out there that have gone undiagnosed due to inequities in health care, Shenouda said. For example, Black children were 30% less likely to be identified with autism without intellectual disability than [white children](#) in the New York/New Jersey area, results show.

Further, children living in well-to-do areas were 80% more likely to be identified with autism without intellectual disability than children living in poorer places.

"Even though identification among underserved groups is improving over time, the study shows that there are still disparities in identification of autism without intellectual disability among some groups in the population," Shenouda said.

Both Shenouda and Hotez said it's still not clear whether the increase in autism diagnoses is occurring because of improvements in screening or because there are more kids developing autism.

"It's a combination of both," said [Wendy Fournier](#), president of the National Autism Association. "There is greater public awareness of early signs of autism, making parents more likely to address developmental concerns with their doctors, and actual prevalence rates are continuing to rise at alarming rates year after year."

Experts are getting better at detecting autism, particularly when it isn't accompanied by an [intellectual disability](#), Shenouda said. There's also been progress made addressing disparities that hinder diagnosis of Black and Hispanic children with autism.

But there's still not enough screening being done, Shenouda said.

"I do think to a large degree what's recommended by the American

Academy of Pediatrics, which is screening at ages 18 months and 24 months, isn't really happening," Shenouda said. "If there is one thing that would be a takeaway of all of this is that universal screening of autism wouldn't just identify children early, but it's likely to improve identification among underserved communities as well."

There's also not enough data available regarding how social, economic and community factors influence [autism](#) and its diagnosis, Hotez said.

"Because we're missing that critical piece, we don't quite understand why exactly Hispanic [children](#) might be identified at different rates, or why underserved families might be receiving different rates of diagnoses," Hotez added.

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The U.S. Centers for Disease Control and Prevention has more about [autism prevalence](#).

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